



June 28, 2024

Therese Miller, Dr.P.H.
Director
Center for Evidence and Practice Improvement
Agency for Healthcare Research and Quality
5600 Fishers Lane
Rockville, MD 20857

Subject: Draft Interventions to Improve Care of Bereaved Persons Report

Dear Director Miller,

Thank you for your commitment to developing consensus-based standards for grief and bereavement care. On behalf of our more than 5,400 nonprofit and mission-driven aging services providers from across the continuum of aging services, including hospice and affordable seniors housing, and our 36 state partners in 41 states, LeadingAge is pleased to offer the following comments on the Agency for Healthcare Research and Quality's (AHRQ) Draft Interventions to Improve Care of Bereaved Persons Report.

Bereavement support is critical for both older adults and aging services providers as we navigate grief in various forms, and we applaud the work of the Center in elevating standards for bereavement services. As the leading voice for aging in America, we value the opportunity to provide comments and to work together to advance improved grief assessment and intervention services for older Americans.

General Comments on the Draft Report

First, we are pleased to see this report and the beginning of this work. LeadingAge worked closely with Congress to obtain the appropriation to support this work in order to move toward consensus-based standards for high quality bereavement care. It is a critical component of care, and the ability to assess its effectiveness is something our members have asked for as part of our advocacy efforts. Grief impacts older adults across the continuum of aging services, and our provider members witness daily the profound impacts of loss and grieving in the communities they serve.

LeadingAge was instrumental in crafting the language that accompanied the funding of this project through the 2023 federal appropriations process. We specifically highlighted the impact of the COVID-19 pandemic on grief and loss and included language to consult hospice programs as part of establishing an evidence-base.

Grief and Bereavement Care—The agreement notes that more Americans are experiencing grief and loss as a result of the COVID–19 pandemic. The agreement includes \$1,000,000 to fund an evidence review and technical expert panel to assess the feasibility of developing consensus-based quality standards for high quality bereavement and grief care. AHRQ is directed, in consultation with stakeholders including the National Quality Forum (NQF), the Patient-Centered Outcomes Research Institute (PCORI), and community-based providers including

hospice programs, to establish an evidence-base on what constitutes high-quality grief and bereavement care.¹

Hospice providers specifically have deep knowledge and experience in the field of grief and bereavement care. Additionally, hospice is the only federal health care program required to provide bereavement services as part of the Conditions of Participation (CoPs) in the Medicare program. However, this service is not reimbursable through Medicare. Since hospices are known to the broader health care community as the source for support with bereavement, nearly all of our hospice provider members offer bereavement services outside of the required services for families of patients who received hospice services. These types of services are available more broadly for members of the local community. For example, the Central Ohio Grief Care Coalition was developed out of the efforts of hospices to consolidate resources for bereavement support and to reduce the duplication of services to ensure stewardship of limited community resources.² Ohio is not alone in attempting to share information and opportunities among the bereavement support community: Nearly every state supports a type of bereavement coalition or similar community-directed work.

While nonprofit hospices take seriously their duty to provide robust bereavement services as part of the benefit, others do not and instead offer cursory programs that do not succeed in meeting the needs of bereaved individuals.³ We hope as part of this work, we can move toward consensus-based standards that would allow for further distinction between high quality and low quality bereavement services that could, in turn, allow for potential reimbursement in the future.

Grief in Many Forms and Settings

In addition to working with our hospice members to understand their role in bereavement services, we spoke with our affordable senior housing provider members, who expressed concerns about unresolved grief in their federally-subsidized housing communities. Many housing staff were concerned that they were not doing a good job of assessing and recognizing grief among their residents. Like many community organizations, affordable housing providers rely on the support from local hospice providers but most housing staff report feeling unprepared to support residents with grief.

In addition to grief related to death and dying, a significant issue experienced in the housing space is related to “Disenfranchised Grief,” which may be unrelated to the death of another individual. Many older adults served by our affordable housing members, and older adults in general, experience losses of identity and independence as they age, as well as grief related to their own health diagnoses.

There is currently a critical lack of mental health services for older adults in federally-subsidized housing, including bereavement support services. Many older adults also experience compounding grief along with isolation and loneliness, which is an increasingly critical health issue for older adults that was exacerbated by the public health emergency and was painfully present in affordable senior housing communities, most of which lack digital connectivity capabilities. Services Coordinators in affordable housing – similar to a social worker who assists older adults as they age in community – feel unprepared to help residents through these stages of life and are ill-equipped to recognize when grief evolves into

¹ Consolidated Appropriations Act, 2023. Legislative text and explanatory Statement.

<https://www.congress.gov/117/cprt/HPRT50348/CPRT-117HPRT50348.pdf>

² Central Ohio Grief Care Coalition. <https://www.thecaregivingtree.com/central-ohio-grief-care-coalition>

³ [42 CFR 418.204\(c\)](#)

significant mental and physical health issues. Service Coordinators are not medical professionals with the ability to diagnose residents; they crave practical information on recognizing and assessing grief in addition to helping residents access supportive interventions.

It is essential that the consensus-based standards developed by this project are applicable to every setting where grief exists. From schools, to workplaces, to federally-subsidized housing, to nursing homes – grief and bereavement has no boundaries. Access to wide-ranging screening, assessment, intervention, and treatment resources and services must be a priority goal of this program.

Comments on the Executive Summary Section of the Draft Report

The executive summary states that one of the deficiencies found in the draft report was “none of the identified studies used a gold standard references of either the DSM or ICD grief disorder diagnosis.” Based on feedback from our hospice members, we strongly recommend amending this statement, as “gold standard” is not appropriately medicalized and too narrow in this instance.

No hospice that we spoke to used these diagnoses and do not consider them the “gold standard” of care for bereavement services. While the recognition of grief disorders in the ICD-10 and DSM are critical steps to supporting individuals experiencing significant trauma related to loss, it also unnecessarily medicalizes the experience of grief and bereavement and may exclude an individual that does not have a diagnosis or is not at risk of those diagnoses from receiving the same access to treatment and intervention.

Comments on the Introduction Section of the Draft Report

The introduction briefly discusses the potential consequences of the “medicalization” of grief and its characterization as a disorder. Our hospice members share these concerns and worry that associating grief with the ICD-10 and DSM prolonged grief disorder could limit the flexibility of the interventions currently allowed to support individuals – the opposite of our intent in pursuing this work. No hospice members stated that they diagnosed any individual supported by the bereavement services with a grief disorder. While many hospice bereavement counselors are social workers, that is not a requirement of the hospice CoPs. That provides them limited authority to diagnose and prescribe treatment for a disorder.

We strongly believe the approach in the introduction and the focus in the methodology on ICD-10 and DSM was incorrect and that a broader approach is necessary to truly understanding grief in its many forms. The introduction should expand on the implications of focusing on these diagnosis and present alternatives to capturing effective bereavement and grief screenings, assessments, resources, and interventions.

We also would like to note that the introduction lacks a thorough discussion of the difference between grief and bereavement. As the first citation notes, they are often used interchangeably but are not the same. For the consistency and clarity of the final report, we believe that AHRQ should clearly articulate the difference and identify how each will be used throughout the report.

Comments on the Methods Section of the Draft Report

As mentioned previously, bereavement, especially for older adults, can include experiences beyond the death of people close to them. Grief can impact anyone diagnosed with a severe or terminal illness, who

has lost independence, or suffered a life-changing event, and challenges resulting from those events can be as complex as the loss of a loved one. We strongly encourage AHRQ to amend the eligibility criteria for studies to include other forms of bereavement beyond the loss of a loved one.

We also note again that using the ICD-10 and DSM clinical diagnoses to identify eligible studies limits the type of grief covered by this work since both diagnoses are specific to the loss of another human. While we are not clear if this will result in any additional research available for the development of the consensus-based standards, people experiencing this type of non-death bereavement and grief deserve recognition in this effort.

Comments on the Discussion Section of the Draft Report

Based on our members' experiences in the field of hospice and aging services, we agree strongly with the implications laid out in the discussion section of the draft report. More research is needed to identify effective approaches to screening. For populations that do not select or indicate bereavement based on an interaction with the health care system, such as those who experience grief in a non-medical setting like an affordable housing community, there is merit in looking at other assessments and screening tools when building out the consensus-based standards. As we stated before, grief has no boundaries, and making sure that professionals in other spaces of society have access to information to conduct potential grief and bereavement screenings is key to supporting the entire population.

While we continue to take issue with the term "gold standard," we do agree more research is needed to evaluate the accuracy of tools to identify bereaved persons at risk for or with grief disorder. This research should incorporate alternative, existing resources such as the Lubbins Social Network Scale, a self-reported scale measure of social engagement including family and friends. We heard time and time again from bereavement teams at hospices that current assessments tools do not capture resiliency and coping ability, including through the social support networks an individual may have. When this is taken into account in current diagnostics for hospices, individuals who would normally score "higher" (more at-risk) on a bereavement assessment due to the severity of the loss can actually be less likely to develop a clinically diagnosable disorder because of their limited coping skills and lack of social networks. Alternatively, someone who may score "lower" (less at-risk) on a bereavement assessment may experience more risk of disordered grief due to the lack of coping skills and support networks.

Finally, we concur with the need for additional research on the timing of interventions and the differential effectiveness of interventions among subgroups. Regarding timing, the report notes that grief is cyclical and does not have linear timing. We heard from many hospice members who are approached by grieving family a year or more after the death of a loved one. According to the hospice CoPs, bereavement counseling must be offered for up to one year after the passing of a loved one. It would be helpful to have evidence to assess whether this standard needs updating.

As we shared, many of our members across the country are part of coalitions that consolidate resources and refer to each other for specialized support groups, such as groups for children or widows or mass casualty events. Unfortunately, these organizations are doing the best with what is available to them and have limited evidence to construct the most effective grief interventions for each population.

We greatly appreciate the opportunity to provide comments on this draft report. We look forward to AHRQ continuing its work on this topic and its resulting partnership with the Substance Abuse and

Mental Health Services Administration to develop consensus-based standards for high quality bereavement and grief care.

Sincerely,

A handwritten signature in blue ink, appearing to read 'Katy Barnett', enclosed within a light blue oval shape.

Katy Barnett

Director, Home Care and Hospice Operations and Policy

kbarnett@leadingage.org

About LeadingAge: We represent more than 5,400 nonprofit and mission-driven aging services providers and other organizations that touch millions of lives every day. Alongside our members and 36 partners in 41 states, we use applied research, advocacy, education, and community-building to make America a better place to grow old. Our membership encompasses the continuum of services for people as they age, including those with disabilities. We bring together the most inventive minds in the field to lead and innovate solutions that support older adults wherever they call home. For more information, visit leadingage.org.

